

**Retention of Transgender, Gay/Bisexual, and Heterosexual Youth
in an HIV Risk Reduction Program¹**

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ABSTRACT

This paper examines the ability of an HIV risk reduction clinic – with special services for male-to-female transgender youth – to keep youth connected to care. Data from 381 youth (45 HIV-positive) were categorized by HIV status and by gender/sexual orientation (gay/bisexual males, heterosexual males, heterosexual females, and transgender youth (male-to-female)). Retention in services was studied using survival analysis. HIV-positive youth were retained in the clinic longer than youth of HIV-unknown or HIV-negative status; transgender youth were retained longer than other youth. Measures of risk behaviors and other demographic factors did not predict retention. Results suggest that such services can retain transgender youth in care at least as long as other youth if targeted, appropriate care is provided.

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Because of their vulnerability of a number of physical, emotional, and social health problems (e.g., James, 1998; Nelson, 1994), transgender youth may require enriched and specialized health care programs (Kreiss & Patterson, 1997). Such specialized services include HIV services (Bockting, Robinson, & Rosser, 1998a) and targeted outreach to this often hidden population (Bockting, Robinson, & Rosser, 1998b). Services for transgender youth need to address the various ways that HIV may affect them (Groomes, 1998). The present paper examines the ability of a medical clinic for high-risk youth, that has been expanded to include special programs for transgender youth, to retain such patients in general care. Within the larger context of developing and providing services for high-risk youth, many of whom have a number of medical and behavioral problems, if a clinic is designed which includes special programs for transgender youth, will these patients find the services attractive and remain active clients of the clinic services?

An Innovative Service Model for High-Risk Youth

The Division of Adolescent Medicine at Childrens Hospital Los Angeles (CHLA) established its HIV Risk Reduction Program in 1988. The program has grown to include community-based HIV prevention and skills-building programs targeting youth (particularly homeless youth and teen parents), HIV antibody testing programs targeting homeless youth, comprehensive healthcare, case management, psychological services for HIV infected youth, and research activities examining the course of HIV infection in youth.

As part of a national service demonstration initiative, CHLA developed and tested a model of HIV care for youth who traditionally lacked access to healthcare and treatment. This

model included 1) targeted outreach to youth living with HIV and those at highest risk; 2) enhancement of youth-specific and youth-sensitive health services providing the full scope of services from HIV testing to HIV care; 3) provision of youth-specific case management and allied health professional services; 4) development of a youth empowerment program; and 5) development of community trainings and workshops to enhance the expertise of community agency staff. Schneir, Kipke, Melchior, and Huba (1998) give a detailed description of the service model.

Within its Risk Reduction Clinic, CHLA developed services specifically targeted to meet the needs of transgender youth. In addition to their unique psychosocial needs, these young people engage in multiple high-risk behaviors and have significant medical, mental health, and case management needs. Although current statistics collected by Los Angeles County and the CDC do not allow for monitoring the prevalence of HIV infection in this gender group, anecdotal information suggests a very high rate. At the Risk Reduction Clinic, transgender youth receive both a medical and a psychological evaluation. A physician conducts a medical history, evaluates hormone use history, collects specimens for routine STD checks, and evaluates hormone levels. A psychologist evaluates the history of gender dysphoria. The physician and psychologist develop and implement a care plan to meet the unique needs of the young person.

In the present context, “transgender” is used as an umbrella term to describe the full continuum of persons in gender transition (male-to-female), including those who are still questioning their gender identity to those who already live as women; from those who have never taken hormones to those who have injected street hormones for years, those who have no desire for sex reassignment surgery, and those who use their penis during sex to youth who are actively seeking to change their bodies. The transgender experience is one of emotional as well as physical transformation. Transgendered individuals can vary across many different social

categories including sexual orientation. While there are exceptions, many transgender youth have been abandoned or rejected by their families of origin and are homeless or precariously housed. These youth are ethnically and racially diverse. In Los Angeles, some of these youth are visible on the streets of Hollywood or downtown, while others are hidden and require innovative outreach strategies to engage them in services.

Given the unique needs of transgender and other youth living with, or at high risk to become infected with HIV, the present study focuses on the evaluation of the ability of the Risk Reduction Clinic to retain such youth in care. It is expected that the program will demonstrate high retention rates for this population, which can be difficult to engage and retain in care. It is also expected that youth with potentially greater medical and psychosocial needs – that is, transgender youth, or youth identified as HIV-positive – will demonstrate greater retention than other youth in the clinic.

METHOD

Characteristics of the Sample

Data were analyzed from a group of 381 youth enrolled in services at an HIV risk reduction clinic for adolescents and young adults. The youth were ethnically-racially diverse (61.7% Latino, 15.7% Caucasian, 13.6% African American, 3.1% Asian American, 0.5% Native American, 2.1% multiracial, and 3.1% unknown) and ranged from 12 to 25 years of age (mean age = 19.2 years, standard deviation = 2.5 years). In this sample, 45 of the 381 youth were known to be HIV-positive, either from testing provided at the clinic or from another source. The present analyses include youth from four mutually exclusive Gender/Sexual Orientation Groups. The sample includes 49 gay/bisexual males, 118 heterosexual males, 163 heterosexual females, and 51 transgender (male-to-female) youth. Lesbian/bisexual women ($n = 19$) were excluded from these analyses due to insufficient data. A total of 8.4% of the youth were identified as

homeless at the time of program enrollment, and 3.9% were identified as being runaways. 13.1% were known to have some involvement with the mental health services system, and 2.6% were involved with the criminal justice system. A detailed description of the sample characteristics is provided in Melchior, Huba, Schneir, Radzik, Belzer, and Panter (1999).

Measures

Client characteristics were recorded by program staff on a Contact Form (Huba, Melchior, & the Staff of The Measurement Group, 1994a) at the time of a young person's enrollment into the project, usually at the first clinic visit. Each service encounter provided in the clinic was recorded on an Intervention Form (Huba, Melchior, & the Staff of The Measurement Group, 1994b), which coded the types of services provided during the encounter, who provided the services, referrals made, and topics discussed. Retention was defined as the number of days from the first service encounter to the last.

In addition to Gender/Sexual Orientation Group and HIV Status, two risk indices were included as predictors of retention. Scores on the Demographic Needs Index can range from 0 to 6 and are incremented by one point if each of six characteristics is known about the individual, including being under the age of 18, a person of color, homeless, a runaway, involved with the criminal justice system, and involved with the mental health service system. The Risk Behavior Index, with scores ranging from 0 to 8, represents a composite of the youth's known involvement in sex with men, sex with women, sex with an injection drug user, sex with an HIV-positive partner, survival sex, having an STD, substance abuse, or injection drug use.

Statistical Analyses

Kaplan-Meier analyses were used to calculate the mean and median retention times for each of the groups based on HIV Status and Gender-Orientation. These analyses were also used to produce retention curves for these groups. The more sophisticated Cox regression model was

used to determine the relative effects of HIV Status, Gender-Orientation Group, and the two needs indices on overall retention patterns. Predictors were entered in two steps: at the first step, the main effects of Gender/Sexual Orientation Group, HIV Status, and the two needs indices were tested. In a second step, two-way interactions of Gender/Sexual Orientation Group with HIV Status, the Demographic Needs Index, and the Risk Behavior Index were tested. Additional relationships between Gender/Sexual Orientation Group and HIV Status predictive of program participation were conducted using ANOVA models. All analyses were conducted in SPSS for Windows, version 9.0 (SPSS, 1999).

In survival analysis, it is necessary to define a censoring event – in this case, when the youth is considered to have left treatment. In these data, cases were considered to be censored if the youth had not been seen in the risk reduction program within 120 days of the last service date in the data. Note that in survival analysis, “censored” means that the client may have continued in the program after the arbitrary date set for terminating data collection and hence this fact is used in calculating “partial credit” in the overall retention curves. In this sample, 44 cases (11.5%) were considered to be “censored” using this criterion.

RESULTS

Figure 1 summarizes the results from the Kaplan-Meier survival analyses for the youth not identified as HIV-positive. Examining the retention patterns for youth of unknown HIV status, gay/bisexual men ($n = 35$) were retained an average of 61.09 days (standard error ± 29.15 days). Heterosexual men for whom HIV status was unknown ($n = 110$) were retained an average of 37.56 days (standard error ± 10.43 days). Heterosexual women of unknown HIV status ($n = 146$) were retained an average of 87.86 days (standard error ± 15.70 days). In contrast to the other youth for whom HIV status was not identified as positive, the transgender youth ($n = 45$) were retained an average of 173.24 days (standard error ± 42.82 days). For the youth of unknown HIV

status, the differences in retention patterns based on Gender/Sexual Orientation Group were significant under the log-rank, Breslow, and Tarone-Ware assumptions ($\chi^2 = 26.36, 37.13,$ and $35.08,$ respectively, all with 3 degrees of freedom and $p < .001$).

Insert Figure 1 About Here

Among the youth identified as HIV-positive, gay/bisexual men ($n = 14$) were retained an average of 405.50 days (standard error ± 116.40 days). Heterosexual men who were known to be HIV-positive ($n = 8$) were retained an average of 194.38 days (standard error ± 45.34 days). HIV-positive heterosexual women ($n = 17$) were retained an average of 341.82 days (standard error ± 41.21 days). Finally, the HIV-positive transgender youth ($n = 6$) were retained an average of 457.63 days (standard error ± 126.50 days). Among the HIV-positive youth, the differences in retention based on Gender/Sexual Orientation Group were not statistically significant ($\chi^2 = 2.66, 2.11,$ and $2.34,$ under the log-rank, Breslow, and Tarone-Ware assumptions, respectively, all with 3 degrees of freedom and $p > .05$). However, it should be noted that the sample sizes get fairly small when examined this way, and thus caution should be used interpreting these findings.

Figure 2 shows the retention curves for the HIV-positive youth in each of the four Gender/Sexual Orientation Groups.

Insert Figure 2 Here

Table 1 summarizes results from the Cox regression analysis. The Cox regression results show that HIV status and Gender/Sexual Orientation Group significantly predict retention in the risk reduction program, $\chi^2(6, n = 381) = 80.64, p < .001$. The main effect for HIV status was

statistically significant, in that youth identified as HIV-positive remained active longer in the risk reduction program. The main effect for Gender/Sexual Orientation Group was also significant. Consistent with the prior analyses, transgender youth were retained longest, followed by heterosexual women. Both groups were retained significantly longer than were heterosexual males.

The effects of the two risk indices were not statistically significant. In addition, the second step, which entered the two-way interactions of Gender/Sexual Orientation Group with HIV Status, Demographic Needs, and Risk Behaviors, was not statistically ($\chi^2(9, n = 381) = 2.88$). Thus these interactions did not further predict retention in the risk reduction program above and beyond the main effects of HIV Status and Gender/Sexual Orientation Group.¹

Insert Table 1 About Here

As a final test of the effects of Gender/Sexual Orientation Group and HIV Status on retention, ANOVA and ANCOVA models were tested to examine the effects of these indicators on the total number of visits to the Risk Reduction Clinic. In a two-way analysis of variance using Gender/Sexual Orientation Group and HIV Status as the independent measures and the total number of clinic visits as the dependent measure, there were statistically significant main effects for Gender/Sexual Orientation [$F(3,373) = 4.63, p < .01$] and HIV Status [$F(1,373) = 118.50, p < .001$], as well as for the interaction of those two predictors [$F(3,373) = 4.67, p < .01$]. Specifically, Tukey HSD post hoc tests indicate that heterosexual males had significantly fewer clinic visits (mean = 2.28 visits, s.d. = 4.50) than gay/bisexual males (mean = 5.49 visits, s.d. = 8.68), transgender youth (mean = 6.07 visits, s.d. = 8.00), and heterosexual females (mean = 4.60, s.d. = 6.90). Youth who were HIV-positive attended the clinic more frequently (mean =

14.31 visits, s.d. = 11.17) than youth of unknown HIV status (mean = 2.84 visits, s.d. = 4.54).

The interaction between Gender/Sexual Orientation and HIV Status indicated that the difference in the number of clinic visits based on HIV status was the largest among heterosexual females and the smallest for transgender youth.

In a comparable analysis of covariance, the same predictors were used, with total time in program (that is, the number of days from the first clinic visit to the last) included as a covariate. Having controlled for the effect of total time in program, the effect based on Gender/Sexual Orientation Status was not statistically significant [$F(3,372) = 1.94, p > .05$]. The effect of HIV Status remained significant [$F(1,372) = 88.74, p < .001$], as did the interaction between Gender/Sexual Orientation and HIV Status [$F(3,372) = 4.72, p < .01$].

DISCUSSION

This study presented a unique opportunity to examine the patterns of retention in care among a heterogeneous group of youth living with HIV, or at very high risk to become HIV-positive. Service utilization patterns of transgender youth have not been studied extensively, and thus this investigation allowed us to examine whether this program – which was developed to meet the complex needs of transgender youth – could successfully engage and retain such youth in care. The findings demonstrate a strong pattern of increased retention for transgender youth, for those who were identified as HIV-positive, as well as those who had an unknown or negative HIV serostatus. Given that the overall retention levels for youth receiving services from the Risk Reduction Clinic were high to begin with, this is a strong finding that indicates the transgender youth were especially bonded to the program. Similarly, the overall effect for HIV-positive youth to remain in care longer than youth not known to be HIV-positive also supports the validity of the model for matching the level of intensity of services to the needs of the young person. As services for youth living with HIV need to be comprehensive, coordinated, and

youth-friendly in order to engage and retain them in care (Huba & Melchior, 1998), the present findings demonstrate that the CHLA Risk Reduction Clinic has been successful in accomplishing exactly that.

Because the CHLA Risk Reduction Clinic had developed specialized services for transgender youth and built a significant following in the community, the present study was an unusual opportunity to study the retention of such youth in a care system specifically designed to meet their unique service needs. The findings presented here suggest that if services are tailored and sensitively provided to transgender youth in a nonjudgmental environment, they will continue to return for services from that provider. Given that the service needs of transgender youth require a complicated balance of medical, psychological, and supportive services, these results illustrate the success of the CHLA model in engaging these young people in care. Of course, other outcomes such as reduction of HIV risk behaviors, improved health and psychosocial functioning, and satisfaction with care are further indicators of the program's success in reaching this complex population. Given that retention in care is highly predictive of other desired treatment outcomes (e.g., Simpson, Joe, & Brown, 1997), it is likely that the program will demonstrate similar successes in these related domains. Further work will examine the outcomes of these youth as a function of their involvement in a continuum of care specifically designed to meet their needs.

In examining retention in care, it is important to consider the youth's motivation for returning to the care provider. In the present study, the various groups of youth differed in their service needs. The high risk heterosexual and gay/bisexual young men with unknown HIV status were often motivated to access clinic services due to urgent medical needs or HIV testing services. Once the identified need(s) were met (often in one or two visits), they had little motivation to return for additional services or maintain on-going contact with clinic staff. High-

risk heterosexual young women may have been retained longer due to family planning issues. In general, young women access health care services at greater rates than young men (e.g., Aten, Siegel, & Roghmann, 1996; Wolk & Kaplan, 1993).

In contrast, transgender youth often seek care to receive hormone therapy. Because hormone therapy is required monthly to achieve and maintain the desired secondary sexual characteristics, the retention of transgender youth in services designed to meet their needs is not surprising. The vast majority of the transgender youth served were highly motivated to meet the service requirements (regular meetings with the medical and mental health provider) necessary for on-going hormonal treatment and other community options for similar care did not exist. While not all of the transgender youth were receiving hormone therapy nor solely motivated by hormone therapy, this factor was very important to the ability of the clinic to retain youth in care. While it may seem obvious that youth can be retained in programs that offer a service that is desired by the specific target populations, too often programs are established based on the problem (HIV prevention, for example) that the funder wants to address rather than on the service motivations of the population. A clinic promoting HIV prevention and testing services only to transgender youth, no matter how sensitive and appropriate the staff, would not have been as successful in engaging and retaining these youth.

Similarly, differential retention rates for HIV-positive youth are not surprising. Messages about the importance of early and on-going health care for individuals with HIV infection have permeated the community. While we can expect that programs specifically tailored for youth with HIV, like the Risk Reduction Program, will be most successful in retaining youth due to sensitive and educated staff, accessible services, and the comprehensive program model, the motivation for returning for on-going care is shared, at least to some extent, by the youth and the care providers.

The present findings indicated that in this clinical sample, other indicators of client characteristics and HIV risk behaviors, such as risky substance abuse and sexual risk behaviors, did not differentiate this sample of high risk youth. Given that the youth were participating in the risk reduction program, and were recruited because of a high risk for HIV and other related health problems, it should not be surprising that these measures do not predict retention among such a homogeneous sample in this regard. Rather, it appears that retention was based on objective healthcare needs (i.e., those of youth living with HIV, young women with reproductive healthcare needs) and features of the program that were particularly attractive to certain target groups (e.g., transgender youth).

One potential confound in studying retention in program for youth is the “aging out” phenomenon. The age range for the risk reduction program was 12-24 years; youth at the upper limit of this range were transitioned to the adult service system. Thus it is unknown whether such individuals would voluntarily choose to end their involvement with the risk reduction program if they were not aging out of the youth service system. Furthermore, clinical observation suggests that young gay men in particular tend to cluster near the upper end of the age range. This age effect may explain the relatively shorter retention of that group in the present study, compared to retention rates for heterosexual women and transgender youth.

The success in retaining these transgender and HIV-positive youth in care suggests that even the most transient, multi-problem, and challenging populations can be retained in care if the providers are well informed about the service needs identified by the potential consumer. Once the consumer is engaged in services that they have identified (and barriers to access have been addressed), other complimentary services can be interwoven into the service model.

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FOOTNOTES

1. To test whether the retention rates changed over time across groups, a second Cox regression analysis was conducted using the same predictors and adding the effect of a time-dependent covariate. The results of this analysis were comparable to those without the time-dependent covariate.

Table 1

Event History (Cox Regression) Analyses of Client Characteristics on Program Retention Rates (n = 381)

Model Step	Model Summary	Individual Model Effects				
	χ^2 Change	R	Wald Test	B	Odds Ratio	95% Confidence Interval for Odds Ratio
Step 1: Main Effects	$\chi^2(6)=80.64^{**}$					
HIV Status		-.10	37.02**	-1.62	.20	.12, .33
Gender/Sexual Orientation Group ^a		---	17.12**	---	---	---
Gay/Bisexual Men		.00	0.01	-.02	.98	.67, 1.42
Transgender Youth		-.05	11.41**	-.69	.50	.34, .75
Heterosexual Women		-.04	8.32*	-.37	.68	.54, .89
Demographic Needs Index		.00	0.90	.07	1.07	.93, 1.24
Risk Behavior Index		.00	1.63	-.06	.94	.85, 1.03
Step 2: Two-Way Interactions	$\chi^2(9)=2.88$					
Gender/Sexual Orientation Group by HIV Status		---	1.27	---	---	---
Gender/Sexual Orientation Group by Demographic Needs Index		---	1.33	---	---	---
Gender/Sexual Orientation Group by Risk Behavior Index		---	0.58	---	---	---

^aContrast groups are compared to retention rates for heterosexual men.

* $p < .05$, ** $p < .01$, *** $p < .001$

Figure 1

Retention of Transgender, Gay/Bisexual, and Heterosexual Youth of Unknown HIV Status in

Care (n = 336)

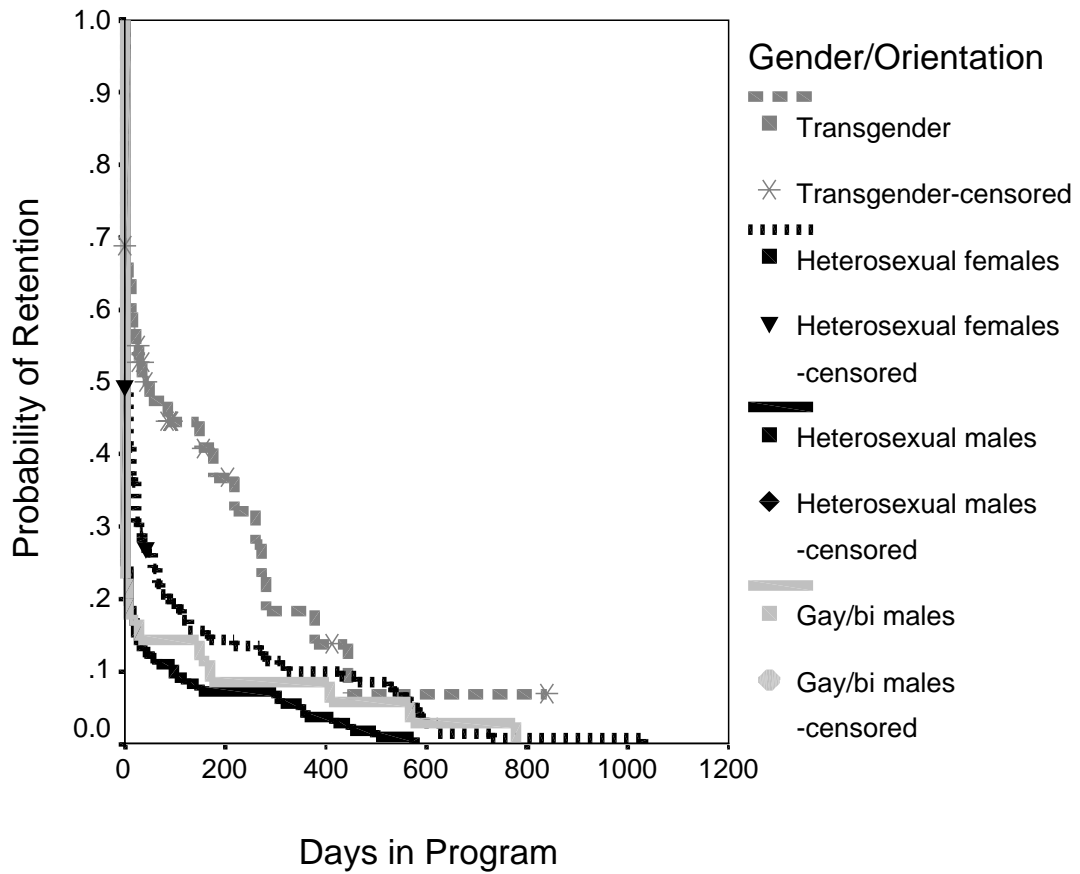


Figure 2

Retention of HIV-Positive Transgender, Gay/Bisexual, and Heterosexual Youth in Care (n = 45)

